ESTUDOS DE PSICOLOGIA
Psychological Studies

THEORETICAL ARTICLE
ARTIGO TEÓRICO

Health Psychology
Psicologia da Saúde

Editor
Raquel Souza Lobo Guzzo

Conflict of interest
The authors declare they have no conflicts of interest.

Received
October 14, 2020

Final version
August 26, 2021

Approved
December 1, 2022.

Aya Kitou: Resilience capacity according to the Boris Cyrulnik biopsychosocial model

Aya Kitou: capacidade de resiliência segundo o modelo biopsicossocial de Boris Cyrulnik

Stephanie Ginneth Martínez-Rojas[1], Nolly Nataly Castañeda-Ibáñez[1]

[1] Corporación Universitaria Minuto de Dios, Facultad de Ciencias Humanas y Sociales, Programa de Psicología. Bogotá, DC, Colombia. Correspondence to: N. N. CASTAÑEDA-IBÁÑEZ. E-mail: <nolly.castaneda@uniminuto.edu>, <nollynataly@gmail.com>.

Article elaborated from the dissertation of S. G. MARTÍNEZ-ROJAS, entitled "*Factores de resiliencia en el caso conocido de Aya Kitou con base en el modelo biopsicosocial de Boris Cyrulnik*". Corporación Universitaria Minuto de Dios, 2020.

How to cite this article: Martínez-Rojas, S. G., & CASTAÑEDA-IBÁÑEZ, N. N. (2023). Aya Kitou: Resilience capacity according to the Boris Cyrulnik biopsychosocial model. *Estudos de Psicologia* (Campinas), *40*, e200199. https://doi.org/10.1590/1982-0275202340e200199

Abstract

Objective
Spinocerebellar ataxia type 2, an orphan disease also known as spinocerebellar degeneration, is characterized by a degenerative process of the cerebellum and spinal cord.

Method
Biographical review of a Japanese woman known as Aya Kitou, using a qualitative approach of discourse analysis to identify resilience capacity, based on Boris Cyrulnik's Biopsychosocial model.

Results
Description based on the detailed experience reported in Aya´s diary; the areas to achieve resilience are identified (internal resources, sociocultural significance and social support system)

Conclusion
Although the progression of the clinical condition compromised Aya''s functional capacity, limiting her autonomy and quality of life, it was evidenced that thanks to strong social networks individuals are more likely to achieve resilience, although the prevalence of social values and meanings upon the patient creates greater social anxiety and a greater feeling of inferiority and incapacity.

Keywords: Models, biopsychosocial; Emotional intelligence; Quality of life; Resilience, psychological; Spinocerebellar ataxia.

Resumo

Objetivo
A ataxia espinocerebelar tipo 2, uma doença órfã também conhecida como degeneração espinocerebelar, é caracterizada pelo processo degenerativo do cerebelo e da medula espinhal.

Método

Revisão biográfica de mulher japonesa conhecida como Aya Kitou, a partir de uma abordagem qualitativa, baseada na análise do discurso, para identificar a capacidade de resiliência, a partir do modelo biopsicossocial de Boris Cyrulnik.

Resultados

Descritos com base nas vivências detalhadas de seu diário, são identificadas as áreas para alcançar resiliência (recursos internos, significado sociocultural e sistema de suporte social).

Conclusão

Embora a progressão do quadro clínico tenha comprometido sua capacidade funcional, limitando sua autonomia e qualidade de vida, evidenciou-se que, graças às fortes redes sociais, tem mais chance de alcançar resiliência, embora, com a prevalência de valores e significados sociais sobre ela, haja maior ansiedade social e maiores sentimentos de inferioridade e incapacidade.

***Palavras-chave*:** *Modelos biopsicossociais, Inteligência emocional; Qualidade de vida; Resiliência psicológica; Ataxias espinocerebelares.*

Spinocerebellar Ataxia Type 2 (SCA2) is a clinical condition that is part of a group of neurodegenerative diseases, specifically a hereditary subtype of ataxia, which occurs on the one hand in a dominant or recessive manner and, on the other hand, due to abnormalities in the X chromosome that are characterized by the degeneration of the cells that make up the cerebellum and sometimes the spinal cord (Ashizawa et al., 2018). According to Teive et al. (2019), the disease has an estimated worldwide prevalence of 1.5/100,000, while in Colombia (Traschütz et al., 2019), the prevalence of Autosomal Dominant Spinocerebellar Ataxia and Autosomal Recessive Cerebellar Ataxia is 0.053%. Hence, this condition is considered part of the group of orphan diseases with an intrinsically progressive course in adult-onset subjects (Jacobi et al., 2020).

Ataxia is a characteristic of neurological diseases, that is, a symptom of a degenerative process of the brainstem cells and of the cerebellum, the control center of balance and coordination of body movements; such degenerative process causes a lack of muscle control, affecting voluntary movements, gait and posture (Fernández et al., 2013; Jacobi et al., 2020; Naito et al., 2017), thus requiring an effort by the individuals to correct and maintain the direction of their movements, which presents, in addition to ataxia, many other symptoms that vary according to the type of ataxia; in other words, the disease presents multi-systemic alterations with an accelerated progression of the degenerative process (Velázquez Perez, 2015).

Within the psychological manifestations (Alves-Cruzeiro et al., 2016; Robertson et al., 2016) similar signs are mentioned in relation to mental disorders or psychological alterations with a prevalence of depression and anxiety; the first one is the relationship between personality and energy, and consists of a habitual variation in mood that persists and interferes with everyday activities, which, according to the American Psychological Association (2017) and Sullivan et al. (2019) may include pain, guilt, fatigue, changes in sleep patterns, poor attention, concentration and memory, thoughts of death or suicidal ideation, among others. While, anxiety is an emotional reaction, subjective, physiological, and behavioral responses, which occur in threatening situations as an adaptive mechanism, may also cause weakness or fatigue.

In general, the treatment of SCA2 is aimed at reducing the progression of the disease and improving quality of life (Orozco Gómez & Castiblanco Orozco, 2015); those authors mention the development of coping skills or strategies, seeking to give meaning to life and sense of identity; thus cognitive-behavioral therapies provide strategies to understand thoughts and emotions to cope with pain and the importance of psychosocial resources, of support networks and social networks is inferred, since their participation is determinant to avoid relapses and improve symptoms (Alves-Cruzeiro et al., 2016; Maturana, 2011).

From this initial contextualization of spinocerebellar ataxia, an interest then develops to identify the resilience capacity of a patient with this diagnosis, especially in the known case of Aya Kitou, since psychology (Baumbusch et al., 2018; Laborda, 2019; Ris et al., 2020) is committed to promoting resilient skills for managing a new reality, in order to protect and generate adaptation in psychological terms and also reduce vulnerability in other aspects of the physical health, which implies a restructuring of behaviors, thoughts and management of emotions, favoring empowerment, self-realization and self-confidence, which should improve the quality of life of those who suffer from this disease and their families (Liu et al., 2020; Silva et al., 2021).

Thus, it is sought through the biopsychosocial model of Boris Cyrulnik (Cyrulnik & Fairfield, 2010), to carry out an analysis of the discourse entered in Aya's diary, describing the internal resources, the sociocultural significance and the social support systems, areas which are suggested for developing resilience based on this model, in relation to the concept of disease and/or disability and the narrative construction of the experience, without forgetting also, that we start from a medical diagnosis of a rare disease (Greaves & Hunt, 2017; Wei et al., 2020).

Method

Single case study, which arises from the need to understand a particular phenomenon within a particular spatiotemporal context, from its description and/or analysis (Butler & Cartier, 2018), because it facilitates the understanding of the history and the meanings given by the patient about the experience of the orphan disease, which are based on historical and cultural references that become the central area of analysis in this case.

The case of Aya Kitou

This case study is about a Japanese woman who died at the age of 25, ten years after being diagnosed with Spinocerebellar Degeneration (Spinocerebellar Ataxia), who recorded her personal experience in a journal, titled One Liter of Tears; which was first published in Japan on February 25, 1986, two years before her death. Spinocerebellar degeneration (Spinocerebellar Ataxia) is a neurological disease that has no specific cause and no cure.

Sánchez Gómez (1896/2013, p. 11, own translation) describes in the prologue:

> The disease took everything Aya had. She was not able to practice sports again, she stopped going to school because the use of a wheelchair did not allow her to follow a routine; she lost her friends; it was more difficult for her to write to the point of producing an unintelligible handwriting; she choked while eating or just by swallowing saliva; it became impossible for her to express what she felt, what she wanted to say, and in the end, she was not able to speak any more.

At the age of 15, due to the first manifestations of the disease such as loss of weight and balance, dizziness, changes in the way of walking and slow movements, she was diagnosed with this condition by means of a computed tomography scan at the Nagoya National University Hospital. She had increased difficulty walking, loss of muscle tone and strength of her arms and legs, difficulty eating due to choking; she was then hospitalized at around 16 years of age. Even so, she began rehabilitation, which consisted of coordination exercises, alternation of movements between the different members of the body and gait but experiencing headache and nausea after performing the treatment.

Subsequently she could no longer utter loud sounds, with no possibility of moving her arms and legs, with increased loss of muscle tone and strength, and difficulty writing; hence, the process of changing from a regular educational institution to an institution for people with functional diversity began. At Okayo Institute (Okazaki Institute for the Physically Handicapped of the Aichi Municipality), her leg mobility progressively decreased with burning pain in the right leg and knee; pain began on the inner side of her hip with involuntary movements in the left hand, pain on the left side of the chest, in the arms, joints and in the right buttock.

At around seventeen years of age, she presented greater impediment in the mobility of her hands, loss of strength in her legs and feet, becoming difficult to stand on her tiptoes; during the summer vacations there was an increase in the slowness of words pronunciation, with choking even when drinking; she had blown to the body due to falls, numbness in the Achilles heel making it difficult to move the legs forward and loss of strength of the abdominal muscles, although after taking a medication (they do not mention which one) it was easier for her to increase walking speed and the muscles of her right leg were relaxed; swallowing improved, although she still had difficulties and pain moving her legs, plus the limitation in the pronunciation of the syllables ba, wa and ma, because the muscles of her mouth presented a tic.

At the beginning of the new year, she could not pronounce the n sound anymore; only air came out of her mouth; she could no longer hold chopsticks to eat because the thumb of her right hand did not stretch enough, and the other fingers were stiff and did not move. The vision got blurred; there were changes in the shape of the right foot, dominance of the protruding big toe while the other toes laid flat; she experienced progressive loss of walking ability, of abdominal strength and lung capacity.

In a second hospital stay, the involuntary movement of the eyes to the sides became more visible. When she fixed her gaze to the right, her vision became blurred and divided the objects; if she set her gaze to the left, the level of distortion was reduced but the speech disorder continued to worsen. For the rehabilitation process, she began to use crutches, perform manual works, and practiced to repeatedly sit on a chair and stand up. She experienced greater hand stiffness, making it difficult for her to open and close them; she also experienced the presence of facial twitching. After graduating from the Okayo Institute, she had her third stay in the hospital and to improve her lung capacity she began to play the harmonica, but during rehabilitation she kept her back twisted and her upper body leaned forward in order to gain strength to be able to move a little more by herself; however, due to the degeneration of certain abilities, she began to eat shredded food.

At the end of the hospitalization process, she began by herself a rehabilitation process that involved standing up, raising her pelvis, turning, and sitting up ten times, obtaining support from one side to the other, raising her arms for five minutes, holding on to something for five minutes, inhale and exhale deeply three times. She knitted and performed manual activities to exercise her hands and recite picture books to work on speech, which, by late fall, caused a decline in energy and resistance.

When nineteen years old, a notable loss of sphincter control develops; there is a decrease in the time to carry out rehabilitation due to other types of activities of greater interest to her; by spring she could not stretch her Achilles tendon and it was difficult for her to sit down; her tongue movements became weaker, there was a complete loss of the ability to walk, numbness of the shoulder joints and inability to raise the right arm. As her condition progressed, more limitations developed in her ability to read, use a pencil, and see objects. Since she was admitted to the Akita hospital, she required permanent assistance for the different activities of daily life such as turning over in bed, going to the bathroom, dressing, undressing, eating, sitting, among others; pronunciation and reading became difficult and her writing was now totally illegible.

At the age of 20, Aya could no longer continue writing due to the total immobility of her body, so information covering the period between her 20-25 years of age is unknown; what could be found about the case are the perspectives or experiences during that time of her mother, her father, and her doctor, as referred to in the book, "When she realized that she would never be able to walk again, she lost her speech and, ten years after the diagnosis, on May 23, 1988, at 12:55 p.m. she died at the age of 25" (Sánchez Gómez, 1896/2013, p. 9, own translation).

Instruments

Aya Kitou Diary – We worked on the Spanish version of Aya Kitou's diary, with translation and publication by David Sánchez Gómez (Sánchez Gómez, 1896/2013). A transcription matrix was developed that allowed organizing the narration of the experiences of each point in time of Aya's life cycle, based on categories such as: 1) experience, 2) internal resources, 3) sociocultural significance and 4) support networks, as well as a categorization matrix to locate the story in order to identify the relationship that this narrative had with the categories proposed. Thus, there is here a division by category (columns) and by narrative concept (rows).

Procedure

The case study was defined as being of interest with the search for information on Spinocerebellar Ataxia, as this is a rare condition, classified as orphan disease and of low prevalence, in order to acknowledge the understandings that have been built around the phenomenon. The importance of the social impact of this disease was recognized, leading to broaden the perspective from psychology, generating disciplinary and interdisciplinary knowledge, addressing the need to build resilience around the disease. A matrix was built for the collection of information and subsequent interpretation through the categorization of said information. In the results construction phase, Aya Kitou's experience was reflected in Tables 1, 3, 4, and 5, which allowed the discussion to begin, in which the postulates of the biopsychosocial model were reported.

Analysis Schedule

A discourse analysis is carried out, in which language is considered a medium that expresses and participates in the nature of social reality (Boréus & Bergström, 2017; Núñez, 2019); working from a categorical analysis, based on a conceptual system, where the statements that should be presented are collected. The process starts from spheres such as linearity, meaning and understanding of the world (Arias & Alvarado, 2015; Núñez, 2019), thus addressing "disease and/or disability" and the "narrative construction of the experience", concepts for reconstructions of reality around the experience of the disease, from the moments of the life cycle exposed in the diary. Those moments are in relation to the areas to achieve resilience according to Boris Cyrulnik's biopsychosocial model: 1) internal resources, 2) sociocultural significance, and 3) social support systems.

1) Disease and/or disability: Within this category, all those narrations that emphasize the symptoms or changes due to the condition, which bear an impact on the life of the patient who suffers from the disease, were covered, based on the particularity that this disease progresses slowly and there is no known cure or final solution, hoping that these narratives influence the physical and psychological well-being of the patients.

2) Narrative construction of the experience: This category is intended to recreate the experience of chronic illness from the narrative, where we understand that in the relationship between person, family and institution, meanings emerge around the disease that generate forms of organization, thus addressing resilience as a psychological response to the experience.

3) Social support systems: awareness of the narrative structure can help health professionals to identify the patients whose experience of the disease is relevant at a social and scientific level based on the complexity involved.

Research with humans and human cases are necessary components for the development of the different areas of health. For this reason, this review that starts from the psychological discipline considers ethical principles, giving priority to the rights of people, ensuring a harmless action upon them, regardless of whether it is carried out in circumstances associated with healthcare practices or not. As John Rawls, the basic principles of social justice in the work with orphan diseases patients are equal opportunities and the principle of difference, understanding them from a simultaneous relational work, which implies freedom of access to attention in the different social organizations and positions or jobs, not as an imposition on the government, and positively recognize people with functional diversity (Gracia, 2016).

This study will be based in the first place, on the principles of responsibility and competence, ensuring the dignity of the case of interest (El Congreso de la República, 2010), decreed by Ley n° 1090 dated 2006, reported in the Psychologist Code of Ethics and Bioethics (El Congreso de la República, 2006), since there was no direct work with any individual. In addition, both the University and the Psychology program endorsed the completion of the degree work and its subsequent defense.

Results

The results are described based on the experience detailed by Aya Kitou in her diary, through a discourse analysis in relation to her age and the areas of the biopsychosocial model to achieve resilience, as shown in Tables 1, 2, 3, 4 and 5.

Table 1

Analysis of Aya Kitou's resilience capacity when 15 years old

Areas to build resilience	Discourse Analysis - Biopsychosocial Model
Internal resources	Aya recognizes that she does not have a strong personality, generating moments of emotional instability. Hopeful that everything will get better, she gains the strength to endure the changes in her life, despite worrying about how her body looks.
Sociocultural Significance	Not being able to perform some physical movements correctly, she goes through moments of bullying and situations of lack of social empathy towards her, to which she simply takes an avoidant attitude as a way of coping.
Support Network	The doctor understands that the health center is far away from her house; she decides to schedule appointments once a month, Aya takes a positive attitude to do everything right in order to improve. She feels being a burden to her family, so she decides to do everything she can to recover so she can give back. Also, having an unsteady gait, she is more likely to collide with another person, so she decides to move near the walls. When she must make the decision about which academic institute to attend, together with her tutor and her mother, they choose considering that even though her motor skills are not yet seriously compromised and she can attend a public institute, it must be close to her home, due to her situation.

Note: Sánchez Gómez (2013).

Table 2

Analysis of Aya Kitou's resilience capacity when16 years old

1 of 2

Areas to achieve resilience	Discourse Analysis - Biopsychosocial Model
Internal resources	The internal resources begin to weaken since Aya does not understand why that disease has picked her. Based on this uncertainty about her future, she tries to work hard and recognizes that she must find a job that 1) does not involve working with her body, 2) implies more mental work and 3) that the salary allows her to live with dignity. She doesn't want to feel or look miserable before her family and society, so she decides to stop to presume about her abilities in some academic areas..

Table 2

Analysis of Aya Kitou's resilience capacity when16 years old

1 of 2

Areas to achieve resilience	Discourse Analysis - Biopsychosocial Model
Internal resources	When learning that she cannot perform social activities like others, she cries as a form of emotional regulation, beginning to understand the implications of her illness. The increased risk of feeling sorry for the consequences of the loss of strength in her lower and upper limbs makes her wait in safe areas until her family picks her up.
Sociocultural significance	Socioculturally, medical students and people do not realize what this phenomenon may imply in Aya, so they generate actions and comments that frustrate and hurt her. Seeing that she no longer has the support of the academic institution, she changes to the "institute for the disabled", based on an evaluation of pros and cons for her quality of life. Recognizing that she cannot change the past nor stop the time, she feels that she can no longer do anything about her, not as a way of giving up but as a way of acceptance, where study becomes her source of life. To forget Higashikou High School and start being part of Okayo High School, she leaves out of sight items that remind her of her previous school. Having pain in her leg and knee from the blows, she decides to start walking for 10 minutes. To acknowledge that she has a functional diversity, she states that she has to know her limitations and admit that she has a disease, as she also states that she must forget about her healthy past.
Support network	Her mother always acts to improve Aya's social conditions. Not being able to do homework with her friend has led Aya to appreciate her friends as a support network. Since she cannot move easily, she accepts the help of her friends or leans on the walls to improve her gait. By beginning to interact with other students with disabilities, she has learned that 1) she must act to change, 2) she should act to improve what she has, and 3) she should not think only of her mental abilities, or she will only feel miserable.

Note: Sánchez Gómez (2013).

Table 3

Analysis of Aya Kitou's resilience capacity when 17 years old

Areas to achieve resilience	Discourse Analysis - Biopsychosocial Model
Internal resources	At the sports festival, Aya strives to dance and recognizes that things can be achieved if you just try. When she perceives that people can no longer understand her, she decides to stop talking, and cries as a form of emotional regulation on account of her frustration. She develops her new way of eating naturally when she perceives the loss of her orofacial abilities.
Sociocultural significance	She is speechless when she sees that people perceive her experiences as frustration. Aya herself thinks that people had not seen a disabled person, which allowed her to focus on the exhibition, when observing the contemptuous glances of people in the museum.
Support network	She decides to talk to a teacher about her emotions, since she feels a very heavy load.

Note: Sánchez Gómez (2013).

Table 4

Analysis of Aya Kitou's resilience capacity when 18 years old

Areas to achieve resilience	Discourse Analysis - Biopsychosocial Model
Internal resources	Seeing that her clinical condition has not improved a bit, she decides to make an effort with rehabilitation. To start her stay at home after graduation, she decides to conduct an orderly life, with training and adaptation to the family's routines. "As a disabled person, I will have to live my whole life bearing that burden. But I will fight against such burden, even if I suffer (...) that is how I have decided to think" (p. 81).
Sociocultural significance	The best way to repay the attention and love of her family has been by adapting to their routines and doing rehabilitation at home.
Support network	Gratitude for the kindness she has received in her formative years, thus planning to donate her organs when she dies, the only thing she will be able to do for society. She and her mother decide that she should shout, to call the family when she needs help. As for finding a cure, Aya finds out that her doctor hasn't given up and she's still studying to help her, so she continues to struggle with her rehabilitation at home.

Note: Sánchez Gómez (2013).

Table 5

Analysis of Aya Kitou's resilience capacity when 19-20 years old

Areas to achieve resilience	Discourse Analysis - Biopsychosocial Model
Internal resources	Seeing that she can't get to the bathroom when she feels the need to go, she decides to have a schedule, so as not to have accidents.
Sociocultural significance	Recovering menstruation is seen by her as a sign that she is getting better.
Support network	Due to the total deterioration of motor skills, a caregiver is required to help her perform basic activities of daily living.

Note: Sánchez Gómez (2013).

Discussion

Based on the interpretation of the results to achieve resilience (internal resources, sociocultural significance, and social support systems) in the framework of the discourse analysis of the SCA2 experience there reflects the best way to describe Aya Kitou's resilience (Greaves & Hunt, 2017), based on a conceptual system. In this connection, the narrative nature of this woman's life story is recognized, in relation to the concepts: 1) disease/disability and 2) narrative construction of the orphan disease experience, this being the phenomenon that crosses the narrative.

It is recognized that the meanings that are built around a diagnosis of diseases such as SCA2 are configured over time, due to the continuous interaction between multiple cultural and social systems (Höltge et al., 2021); in this connection, Aya Kitou shows in her story a dynamic process in relation to the progress of the clinical condition "My body does not move as I would like" (Sánchez Gómez, 1896/2013, p. 18, own translation), where her actions are governed by a value of social functionality (Table 1, Sociocultural significance), where the discourse according to Michael Foucault cited by Bernasconi (2011) presented an expression of social control and subjectivity, which constitutes and shapes social life. Aya, despite seeing how her capacities degenerate, struggles to maintain an independent life even without managing to live a socially acceptable life.

The recognition that this clinical condition does not have a cure, offers a limitation in the development of the person's life, painful and with physical and mental exhaustion, being determinant in the construction of an identity, especially in an adolescent, where the experience of these changes generated a disorganization in her lifestyle, especially in her school life, "I want to run. I want to study. I want to write more clearly" (Sánchez Gómez, 1896/2013, p. 18, own translation), since by not being able to keep up with the classes and her classmates, she experienced crises, generating impotence, anguish, and fear, directly affecting her way of being (Traschütz, 2019).

The discrepancy between what she says and what she does also leads us to take into account that people are not always directly observed in their daily lives, nor is it possible to recognize as researchers, psychologists and other health professionals, that the narrative produced by people who suffer from these kinds of rare or orphan diseases (Buitrago Malaver & Arias López, 2018), fails to recognize the patients' coping capacity and resilience; even to accompany and cope with the disease from the clinical and social setting.

By not understanding why this clinical condition had picked her up, we perceive in her narrative that there is no emotionality that would allow her to describe or explain how she lived her reality. This affects her independence, her academic productivity (Table 2, Support networks) and family dynamics; such imbalance in her self-concept and her projection of life gets worse by the social vision, trying to live responding to "why do I have to suffer so much?"; and the "how am I going to be happy anyway?" (Cyrulnik & Fairfield, 2010; Núñez, 2019). For Cyrulnik and Fairfield (2010) these questions are essential for a resilient person. Even though the concept of the "disability's" influence framed her in a state of impossibility and incapacity, she finds very solid support networks, both institutional and relational, that accompanied her, allowing space to release her emotions and concerns.

In this way, these spaces and support networks allowed the understanding and acceptance of her reality, causing changes in her relationships, enabling the creation of meeting spaces that allowed her to know herself, so that her day was projected in relation to her abilities. Albeit she knew that the social conception of her would not change, she did manage to generate empowerment based on the hope of being able to improve, changing the way she perceived herself, allowing a different attitude towards the situations she lived in her community, "While I was listening and assuming my illness, I realized that I should start thinking about my future" (Sánchez Gómez, 1896/2013, p. 32, own translation), which is how resilient persons are recognized by the subsequent understanding of their experiences (Cyrulnik & Fairfield, 2010; Wei et al., 2020).

Psychology today must seek other strategies to support and improve quality of life, working together for the development of resilient skills in a person who suffers from a degenerative disease (Maturana, 2011; Silva et al., 2021; Ungar & Theron, 2020; Wei et al., 2020) to promote other types of skills in which self-perception of abilities (Table 4, Internal resources), self-image, body perception (Ruiz-Montero et al., 2020; Teive et al., 2019) and resilience are evidenced "so, Aya, you also have to prepare for a long battle" (Sánchez Gómez, 1896/2013, p. 68, own translation). That could have been for Aya Kitou at that time, a valuable resource within her experience to cope with the disease.

Conclusion

Aya Kitou's life story acquired a sense of transcendence, coherence and meaning, as a legacy for generations of patients and parents, and even more being aware that currently the progression of a degenerative disease has direct consequences on potential alternatives for personal independence, both in identity formation and in cognitive and emotional decision-making by families and institutions. The autobiographical story and her narrative analysis allow the recognition and management of experiences with the aim of providing new and different meanings and methodologies to work with people with this condition.

In relation to this case, we can say that with strong social networks there is a greater probability of achieving resilience and the greater the resilience, the better the quality of life, less anxiety concerning the future and less feeling of sadness for the past, although with the prevalence of social values and meanings about Aya, she develops greater social anxiety and a greater feeling of inferiority and incapacity, which implies that these feelings will play a role in strengthening or weakening her personality.

It is understood that Aya builds her personal narratives in an interpersonal space, being inseparable from the social and cultural context where they occur. Aya's narrative, expressed in written form in her diary, is fundamental in the construction of the experience around the disease; it implies that she constructs her meanings through written language, which is an activity determined in an intersubjective and cultural way and which historically has shown that it can help other people who suffer from the same condition or other similar conditions. Her diary has ruptured the borders of the language and has been read by millions of people, who in a certain way, have benefited from her personal narrative.

It is considered that there are two elements that make comprehensive biopsychosocial care possible: on the one hand, the resilience approach, and on the other, a socio-critical approach to

Aya's experience based on her narrative. Thus, resilience confirms the possibility of adaptation and personal and group growth, providing a framework of action for professional practice, while the story as therapeutic support leads to minimizing personal and sociocultural consequences, focusing those factors that explain these ways of adolescents acting and living and able to move with Cyrulnik's model action. In this way, biopsychosocial care for people with orphan diseases would benefit from inter and multidisciplinary with doctors, social workers, therapists, neurologists, and psychologists, based on a new vision of life and the generation of communication spaces.

This community clinical and social case study enables, first, an understanding of the narrative about the experience of living with an orphan disease. It allows the understanding of a biological and clinical phenomenon in relation to a particular social context and the development of new perspectives of understanding and interpretation of those who suffer from a degenerative disease. It contributes to scientific knowledge from psychology by analyzing the narrative not only of the protagonist, but of other actors around her, as well as the different situations and actions carried out by her in the context, showing the complexity that results for people to understand some phenomena of nature and society, as they appear.

The limitations of this study include the existing misinformation in the clinical and social psychological fields about the proper management and treatment of people with orphan diseases. Secondly, there are limitations related to research on resilience in spinocerebellar ataxia, since the Colombian literature in relation to psycho-emotional aspects and quality of life of people with diagnoses of non-hereditary chronic diseases, have not covered any type of ataxia, let alone aspects such as resilience.

In conclusion, the work in these fields will enable the deconstruction of the discourses on these ill people, promoting individual and social resilience. Although the development of resilience is still a challenge for health professionals for researchers and for a practical application of the knowledge already acquired, and more in the context of rare diseases, the resilience approach is now beginning to take shape, but there is still a lot to learn; this implies the existence of an important field for research that should continue to be explored by Psychology.

It is suggested to continue working based on interdisciplinarity for future research, to continue expanding the visions of work within psychology itself, since as seen in this study, through a methodological and analytical contribution from a clinical and social order, an understanding of the phenomenon studied can be achieved, thus understanding that the different medical conditions can be approached from a biopsychosocial point of view.

References

Alves-Cruzeiro, J. M., Mendonça, L., Pereira de Almeida, L., & Nóbrega, C. (2016). Motor dysfunctions and neuropathology in mouse models of spinocerebellar ataxia type 2: A comprehensive review. *Frontiers in Neuroscience, 10*, e572. https://doi.org/10.3389/fnins.2016.00572

American Psychological Association (2017, May 3). *Superando la depresión*. https://www.apa.org/centrodeapoyo/trastornos-depresivos

Arias, A. M., & Alvarado, S. V. (2015). Investigación narrativa: apuesta metodológica para la construcción social de conocimientos científicos. *Revista CES Psicología, 8*(2), 171-181. https://www.redalyc.org/pdf/4235/423542417010.pdf

Ashizawa, T., Öz, G., & Paulson, H. L. (2018). Spinocerebellar ataxias: prospects and challenges for therapy development. Nature reviews. *Neurology, 14*(10), 590-605. https://doi.org/10.1038/s41582-018-0051-6

Baumbusch, J., Mayer, S., & Sloan-Yip, I. (2018). Alone in a crowd? Parents of children with rare diseases' experiences of navigating the healthcare system. *Journal of Genetic Counseling, 28*(1), 80-90. https://doi.org/10.1007/s10897-018-0294-9

Bernasconi, O. (2011). Aproximación narrativa al estudio de fenómenos sociales: principales líneas de desarrollo. *Acta Sociológica, 1*(56), 9-36. https://doi.org/10.22201/fcpys.24484938e.2011.56.28611

Boréus, K., & Bergström, G. (2017). A*nalyzing text and discourse*: *Eight approaches for the social sciences*. SAGE.

Buitrago Malaver, L. A., & Arias López, B. E. (2018). Los aportes del enfoque biográfico narrativo para la generación de conocimiento en Enfermería. *Index de Enfermería, 27*(1-2), 62-66. https://scielo.isciii.es/scielo.php?script=sci_arttext&pid=S1132-12962018000100013

Butler, D. L., & Cartier, S. C. (2018). Advancing research and practice about self-regulated learning: The promise of in-depth case study methodologies. In D. H. Schunk & J. A. Greene (Eds.), *Educational psychology handbook series. Handbook of self-regulation of learning and performance* (p. 352-369). Taylor & Francis Group.

Cyrulnik, B., & Fairfield, S. (2010). *The whispering of ghosts*: *Trauma and resilience*. OtherPressLlc.

El Congreso de la República. (2006). *Ley 1090 de 2006. Por la cual se reglamenta el ejercicio de la profesión de Psicología, se dicta el Código Deontológico y Bioético y otras disposiciones*. El Departamento Administrativo de la Función Pública. https://www.funcionpublica.gov.co/eva/gestornormativo/norma.php?i=66205

El Congreso de la República. (2010). *Ley 1392 de 2010. Por medio de la cual se reconocen las enfermedades huérfanas como de especial interés y se adoptan normas tendientes a garantizar la protección social por parte del estado colombiano a la población que padece de enfermedades huérfanas y sus cuidadores*. Ministerio de Salud y Protección Social. https://www.funcionpublica.gov.co/eva/gestornormativo/norma.php?i=39965

Fernández, E., Rodríguez, J. L., Rodríguez, D., Crespo, M., & Fernández, J. (2013). La neurorrehabilitación como alternativa esencial en el abordaje terapéutico de las ataxias cerebelosas. *Revista Cubana de Salud Pública, 39*(3), 489-500.

Gracia, D. (2016). Ética de investigación en enfermedades raras. In C. Ayuso, R. Dal-Ré, & F, Palau (Dir.), *Ética en la investigación de las enfermedades raras* (pp. 9-21). Ergon. http://asemcatalunya.com/wp-content/uploads/2018/02/e%CC%81tica-en-la-investigacion-de-las-enfermedades-raras.pdf

Greaves, I., & Hunt, P. (2017). The concept of resilience. In P. Hunt & I. Greaves (Eds.), *Oxford Manual of Major Incident Management*. Oxford University Press. https://doi.org/10.1093/med/9780199238088.003.0002

Höltge, J., Theron, L., Cowden, R. G., Govender, K., Maximo, S. I., Carranza, J. S., Kapoor, B., Tomar, A., Van Rensburg, A., Lu, S., Hu, H., Cavioni, V., Agliati, A., Grazzani, I., Smedema, Y., Kaur, G., Hurlington, K. G., Sanders, J., Munford, R., ... Ungar, M. (2021). A cross-country network analysis of adolescent resilience. *Journal of Adolescent Health, 68*(3), 580-588. https://doi.org/10.1016/j.jadohealth.2020.07.010

Jacobi, H., Du Montcel, S. T., Romanzetti, S., Harmuth, F., Mariotti, C., Nanetti, L., Rakowicz, M., Makowicz, G., Durr, A., Monin, M., Filla, A., Roca, A., Schöls, L., Hengel, H., Infante, J., Kang, J., Timmann, D., Casali, C., Masciullo, M., ... Klockgether, T. (2020). Conversion of individuals at risk for spinocerebellar ataxia types 1, 2, 3, and 6 to manifest ataxia (RISCA): A longitudinal cohort study. *The Lancet Neurology, 19*(9), 738-747. https://doi.org/10.1016/s1474-4422(20)30235-0

Laborda, C. (2019). Promoción de la salud de las personas con enfermedades raras y sus familias: experiencia de abordaje psicosocial. *Revista Clínica Contemporánea, 10*, 1-9. https://doi.org/10.5093/cc2019a6

Liu, J. J., Reed, M., & Fung, K. P. (2020). Advancements to the multi-system model of resilience: Updates from empirical evidence. *Heliyon, 6*(9), e04831. https://doi.org/10.1016/j.heliyon.2020.e04831

Maturana, M. (2011). *Arteterapia y resiliencia: "El arte como terapia de apoyo en un paciente con enfermedad degenerativa"* [Master's thesis, Universidad de Chile]. Repositorio Academico of Universidad de Chile. http://repositorio.uchile.cl/bitstream/handle/2250/101322/ar-maturana_m.pdf?sequence=1&isAllowed=y

Naito, H., Takahashi, T., Kamada, M., Morino, H., Yoshino, H., Hattori, N., Maruyama, H., Kawakami, H., & Matsumoto, M. (2017). First report of a Japanese family with spinocerebellar ataxia type 10: The second report from Asia after a report from China. *Plos One, 12*(5), e0177955. https://doi.org/10.1371/journal.pone.0177955

Núñez, J. (2019). Análisis crítico del discurso Como metodología de comprensión de las ideologías. *Revista Innova Educación, 1*(4), 505-521. https://doi.org/10.35622/j.rie.2019.04.007

Orozco Gómez, A. M., & Castiblanco Orozco, L. (2015). Factores Psicosociales e Intervención Psicológica en Enfermedades Crónicas no Transmisibles. *Revista Colombiana de Psicología, 24*(1), 203-217. https://doi.org/10.15446/rcp.v24n1.42949

Ris, I., Schnepp, W., & MahrerImhof, R. (2020). *Family functioning, family health and social support questionnaire--social support scale; German version (FAFHES)*. APA Psyc Tests. https://doi.org/10.1037/t76647-000

Robertson, E. E., Hall, D. A., McAsey, A. R., & O'Keefe, J. A. (2016). Fragile X-associated tremor/ataxia syndrome: Phenotypic comparisons with other movement disorders. *Clinical Neuropsychologist, 30*(6), 849-900. https://doi.org/10.1080/13854046.2016.1202239

Ruiz-Montero, P. J., Chiva-Bartoll, O., Baena-Extremera, A., & Hortigüela-Alcalá, D. (2020). Gender, physical self-perceptionand overall physical fitness in secondary school students: A multiple mediation model. *International Journal of Environmental Research and Public Health, 17*(18), 6871. https://doi.org/10.3390/ijerph17186871

Sánchez Gómez, D. (2013). *Diario de Aya Kitou. Versión en español*. (Original work published 1986). http://www.ataxia-y-ataxicos.es/LAGRIMAS/Diario-de-Aya-Kitou.pdf

Silva, Í. D., Cunha, K. D., Ramos, E. M., Pontes, F. A., & Silva, S. S. (2021). Family resilience and parenting stress in poor families. *Estudos de Psicologia* (Campinas), *38*, e190116. https://doi.org/10.1590/1982-0275202138e190116

Sullivan, R., Yau, W. Y., O'Connor, E., & Houlden, H. (2019). Spinocerebellar ataxia: An update. *Journal of Neurology, 266*(2), 533-544. https://doi.org/10.1007/s00415-018-9076-4

Teive, H., Meira, A. T., Camargo, C., & Munhoz, R. P. (2019). The Geographic Diversity of Spinocerebellar Ataxias (SCAs) in the Americas: A systematic review. *Movement Disorders Clinical Practice, 6*(7), 531-540. https://doi.org/10.1002/mdc3.12822

Traschütz, A., van Gaalen, J., Oosterloo, M., Vreeburg, M., Kamsteeg, E. J., Deininger, N., Rieß, O., Reimold, M., Haack, T., Schöls, L., van de Warrenburg, B. P., & Synofzik, M. (2019). The movement disorder spectrum of SCA21 (ATX-TMEM240): 3 novel families and systematic review of the literature. *Parkinsonism & Related Disorders, 62*, 215-220. https://doi.org/10.1016/j.parkreldis.2018.11.027

Ungar, M., & Theron, L. (2020). Resilience and mental health: How multisystemic processes contribute to positive outcomes. *The Lancet Psychiatry, 7*(5), 441-448. https://doi.org/10.1016/s2215-0366(19)30434-1

Velázquez Pérez, L. (2015). Nueva era en las investigaciones e intervención sobre la ataxia espinocerebelosa tipo 2. *Correo Científico Médico, 19*(4), 598-604.

Wei, H., Hardin, S. R., & Watson, J. (2020). A unitary caring science resilience-building model: Unifying the human caring theory and research-informed psychology and neuroscience evidence. *International Journal of Nursing Sciences, 8*(1), 130-135. https://doi.org/10.1016/j.ijnss.2020.11.003

Acknowledgments

We are grateful to Marcela Campos-Sánchez for the critical review of the manuscript. We wish to acknowledge Semillero REDES Neuropsicología y Calidad de Vida (Corporación Universitaria Minuto de Dios - UNIMINUTO) for the time spent in meetings and in sharing ideas around this article topic.

Contributors

S. G. MARTÍNEZ-ROJAS is the main author who worked in the conception, design and writing of this article and the co-author N. N. CASTAÑEDA-IBÁÑEZ contributed to the development of the topic, revision, and approval of the final version of the manuscript.